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## Lessons Learned: Feasibility of a Discussion Prompting Tool to Increase Fertility Risk Discussion Among Adolescent Oncology Families

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## Lessons Learned: Feasibility of a Discussion Prompting Tool to Increase Fertility Risk Discussion Among Adolescent Oncology Families

### Abstract

The purpose of this study was to explore the feasibility of distributing a prompting tool (stress egg) in order to increase discussions about fertility risk and preservation (FP) among female adolescent oncology patients, parents, and healthcare providers (HCP). 200 eggs were distributed to four pediatric oncology centers. Qualitative interviews were completed with healthcare staff (N=7) after 6 months of distribution to newly diagnosed female oncology patients ages 12-18. Interviews showed that the main barriers to distribution of the prompt were: forgetting to distribute the eggs; uncertainty about the significance of fertility; and uncertainty about fertility issues in general for female adolescent cancer patients. The scientific community must continually explore effective avenues of communication to ensure such information is received. The stress egg has potential to impact a cancer survivor's outlook on future partnering, family life, and self-concept when used in conjunction with policy.

### Keywords

Decision Prompt, Fertility, Pediatric Oncology, Discussion

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## **Lessons Learned: Feasibility of a Discussion Prompting Tool to Increase Fertility Risk Discussion Among Adolescent Oncology Families**

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*The purpose of this study was to explore the feasibility of distributing a prompting tool (stress egg) in order to increase discussions about fertility risk and preservation (FP) among female adolescent oncology patients, parents, and healthcare providers (HCP). 200 eggs were distributed to four pediatric oncology centers. Qualitative interviews were completed with healthcare staff (N=7) after 6 months of distribution to newly diagnosed female oncology patients ages 12-18. Interviews showed that the main barriers to distribution of the prompt were: forgetting to distribute the eggs; uncertainty about the significance of fertility; and uncertainty about fertility issues in general for female adolescent cancer patients. The scientific community must continually explore effective avenues of communication to ensure such information is received. The stress egg has potential to impact a cancer survivor's outlook on future partnering, family life, and self-concept when used in conjunction with policy. Keywords: Decision Prompt, Fertility, Pediatric Oncology, Discussion*

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Infertility is a potential late effect from cancer treatment, however, there are a variety of options that assist in preserving reproductive potential. These options are most efficacious when initiated prior to treatment (American Society for Reproductive Medicine, June 2005). For females, there are a handful of options that may be considered for fertility preservation: embryo (fertilized egg) freezing, ovarian transposition (surgically relocating the ovaries away from the field of radiation), oocyte (immature egg) retrieval and freezing, and ovarian tissue freezing (the tissue is removed, frozen and then reimplanted) are fertility preservation (FP) options that may be considered (Lee et al., 2006). For pediatric patients, the options available require additional decision-making, such as embryo freezing, use of experimental procedures, and the possibility of delaying treatment.

Evidence shows that newly diagnosed cancer patients of all ages appreciate both the information about potential loss of fertility due to treatment and the option of fertility preservation, even if they do not elect to use it (Letourneau et al., 2012). Patients who received fertility preservation counseling prior to treatment show improved quality of life and less decisional regret in the future, whether or not they used fertility preservation (American Society for Reproductive Medicine, 2013).

Groups such as the American Society of Pediatrics, the National Comprehensive Cancer Network, and Children's Oncology Group have published guidelines indicating the responsibility of physicians and the treatment team to discuss fertility issues with patients of reproductive age (Coccia, et al., 2012; Fallat & Hutter, 2008, Landier et al., 2004). Additionally, these guidelines call for the discussion of fertility preservation options to take place prior to the start of therapy and to continue this discussion into survivorship.

Despite the availability of options, as well as information about risks and financial subsidies, discussions about FP are lacking in pediatric settings (Vadaparampil et al., 2008). Barriers to discussing fertility with pediatric patients include ethical concerns about offering experimental fertility procedures to minors, timing of treatment, physician discomfort, lack of role awareness within an institution, and perceived family receptiveness (Vadaparampil et al., 2008). Despite these barriers, female adolescent oncology patients and survivors report frequently thinking about future childbearing, and have reported interest in methods that could preserve the ability for biological parenting in the future (Nieman et al., 2007). Patients who did not receive fertility preservation counseling and later experience infertility may exhibit low self-esteem, social isolation, poor identity development, regret, guilt for current or future partner, or fear of never finding a partner in the future (Crawshaw & Sloper, 2006). Discussions about FP and the opportunity to store reproductive material prior to treatment may contribute to emotional well-being during survivorship (Ginsberg, 2011).

Patient and family education about fertility risks and preservation options may help to reduce future unfavorable quality of life issues within this unique population. There is an ongoing need to identify how to best educate potential infertility to pediatric oncology patients and families in a manner that is not threatening, intimidating, or embarrassing during the stressful time surrounding a cancer diagnosis. (Lee et al., 2006). Discussion prompts are useful stimuli to introduce a topic, link concepts, and elicit questions (Bute, 2007; Doshier & Rosedale, 1989; Ratcliff & Mckoon, 1988). Prompts can empower the receiver to inquire about the information, but not necessarily interpreting the stimuli as directive. Discussion prompts are useful for education and decision making, and can be valuable at both the conscious and sub-conscious levels (King et al., 2008).

This study sought to examine the feasibility of distributing a prompt aimed at introducing the topic of fertility to pediatric oncology families. Through interviews with HCP, we examined the number of eggs distributed, and how this assimilated with current practices in order to identify lessons that may inform future studies.

Developing strategies to implement and track adherence to guidelines is a continually evolving process. It is important for researchers and clinicians alike to understand methods that are both successful and unsuccessful. This will assist in providing the larger HCP community with more effective tools to improve patient-centered care. As clinicians, it is our goal and obligation to assist in this improvement.

## **Materials and Methods**

Data validity was established by employing four distinct mechanisms: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

**Credibility:** Interviews were obtained from consented informants who engage directly with patients and other HCPs. Queries about the stress eggs were targeted at personal experiences and representative views from the oncology practice in which they were distributed. Informants were elected by the principal investigator at each site.

**Transferability:** Data was ensured to be transferable by providing stress eggs at four geographically diverse sites in order to explore divergent themes.

**Dependability:** Raw notes were reviewed by three members of the research team, and themes were agreed upon to ensure inter-rater reliability.

**Confirmability:** Success of prompt use is unique to the environment and method to which they are employed. A similar study discussed later demonstrates the variability in prompts used for fertility-related discussions which encourages future studies into HCP education to accompany prompt distribution.

The prompt is a 2.5" x 1.75" squeezable foam rubber egg-shaped prompt imprinted with the website and logo for the Oncofertility Consortium on one side, and the acronym "TALK" on the other (Figure 1). The acronym stands for, "Talk about the future, Ask your daughter about fertility concerns, Listen to available options, and Keep your doctor informed of your concerns." The research team designed the prompt, "stress egg," to be easily recognizable when placed in bags or folders with other educational information and brochures given to newly diagnosed oncology patients and their families. This, coupled with data from the literature noting low rates of fertility-related discussions among pediatric oncology patients [7] guided the team to create the acronym "TALK" to stimulate a dialogue among patients, families, and HCPs about fertility risks, options, and education materials.

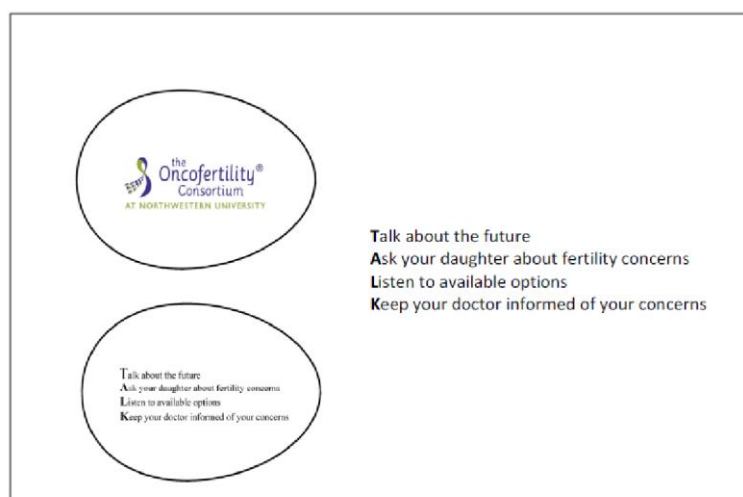


Figure 1. Stress Egg Image

Four pediatric oncology hospitals in the southern region of the United States were provided a total of 200 stress eggs (50 per site). Participating sites were instructed to distribute the stress eggs to new patients (during new patient appointments) along with standard educational materials typically provided to families at each institution in the manner in which the hospital traditionally gives out new patient materials (i.e., placed in new patient bags). Plastic zippered pencil pouches were also provided if the institution distributed new patient binders. Participating staff were instructed to distribute the eggs to newly diagnosed female oncology patients between 12-18 and to maintain the provided log sheet indicating how many stress eggs were distributed, the date of distribution, and comments about the response to the stress egg.

After receiving IRB approval from each institution, the research team conducted qualitative, telephone-based semi-structured interviews (Table 1) with HCP 6 months after distribution. Participants were consented over the phone and received a \$25 gift card for participation. The interviews sought to identify the stress eggs' influence on FP discussions from the HCP perspective. All human and animal protections were followed accordingly.

**Table 1.** Interview Guide

1. In your experience, do you or other HCPs at your institution usually talk about fertility issues with pediatric oncology patients or parents?
• If yes, how do these discussions go? How are these discussions initiated?
• If no, why not?
2. What was your initial reaction to being asked to distribute these eggs?
• How did you think the patients you see would respond to it?
• Did you initially think it would promote discussions about fertility?
• Were you concerned about parent reactions?
• Is there anything that could be done to ensure HCP feel comfortable distributing them?
3. Was the egg given as part of a new patient packet or distributed on its own? or how was it distributed? Did you also provide educational materials such as a brochure or DVD?
• If given on its own, was it given to the parent or patient?
○ What was the reaction of the parent?
▪ Did the parent allow the daughter to see this stress egg?
○ What was the reaction of the patient?
4. After providing the patient/parent with the egg, to your knowledge did they seek out more information regarding fertility?
• If so, what kind of information—question to HCP, internet, literature?
• Who initiated this discussion (parent, patient)?
• Was there any parent-child communication about fertility?
• Did the patients themselves disclose any fertility concerns?
5. If discussions on fertility took place, do you believe they were as a result of receiving the stress egg or something else?
6. If discussion on fertility did not take place, what do you believe the barriers are?
• Based on your experience/institution can you think of possible ways of overcoming these barriers?
7. What is your overall opinion on the usefulness of using these stress eggs to promote fertility related discussions among pediatric oncology patients, parents, and providers?
8. Can you think of other prompting devices that would be more effective than the stress eggs in promoting these discussions?

### **Data Analysis**

Handwritten notes were taken during the qualitative interviews. Responses were analyzed using a combination of content analysis and hand coding to identify unique themes in the content. Reviewer DM abstracted emergent codes from the field notes and collapsed into larger categories. These codes were abstracted from direct quotes from HCP who were asked about perception and responses from patients, families, and staff. Initial categories were compiled into “family perception,” “staff perception” and “distribution.” Themes that emerged in each category were determined by DM and reviewed by GQ and CK for agreement.

### **Results**

After 6 months, 7 eggs were distributed across two sites with the remaining 2 sites reporting that no eggs were distributed, though all sites had representatives that participated in

the follow up interviews. Six registered nurses and one social worker participated in qualitative phone interviews. Demographics can be found in Table 1. All responses detailed below are from nurses, except where indicated. See Table 2 for direct quotes.

**Table 2.** Direct Quotes from Interviews with Health Care Professionals\*

Category	Direct Quotes
Family Perception	<p><i>I had a patient ask what it (the egg) was and if it applied to them. I told her she could go to the website on the egg with her mom to get more information.</i>                      -Social Worker</p> <p><i>About a week after diagnosis and getting the egg I asked the family if they had any questions about anything in their new patient handbook. They mentioned the egg but it was in conversation with everything else... 'I can stay in the Ronald McDonald House, I can do this for stress management, I can go here for questions about fertility...</i></p> <p><i>The family thought it was really cute! I'm not sure if they went to the website but they were definitely playing with it. I'd see it in different places when I'd go into the room.</i></p>
Staff Perception	<p><i>For one patient I gave the egg to, the dad did not want to discuss fertility at all. But having the egg there, him squeezing it in his hands, he ended up being really receptive and it actually ended in an education session about fertility preservation.</i></p> <p><i>I think the staff feels uncomfortable about telling the family they have all these options knowing that the family can't afford it. Is there any financial assistance for these kinds of things?</i></p>
Distribution	<p><i>Because we were only giving the eggs out to girls, we figured we'd put them in the binders as we got female patients. But with so many different nurses working on different days they just forgot about doing it.</i></p> <p><i>The physician always talks about fertility in the family conference so I don't know what I could add.</i></p> <p><i>The social workers are pretty good about covering most things, so if fertility was a concern to the family they'd (the family) bring it up then.</i></p> <p><i>They're (parents) are so worried about their daughter's life I don't think they want to hear about whether or not she can have kids later on.</i></p> <p><i>So if the patient asks me about fertility, what am I supposed to say? I don't even know how I would respond to that question. I guess I'd just tell them to ask the doctor.</i></p>

\*All responses detailed below are from nurses, except where indicated.

### ***Family Perception***

Eggs that were given in new patient binders did not elicit questions about FP (n=4), however families who were given the eggs as a stand-alone prompt (n=3) displayed a positive response and inquired about FP.

All families were agreeable to receiving the egg, and no parent indicated that they were opposed to their child receiving the egg. Families given the eggs in new patient packets perceived the prompt as having parallel value to the other educational material provided.

Families also indicated that the egg was “cute” and effective in getting their attention.

### ***Staff Perception***

Though the intention of the eggs was to prompt and empower the families to ask about fertility, the majority of HCP indicated the eggs worked more effectively as a staff prompt. The egg fostered an awareness of fertility and allowed them to “break the ice” and discuss FP.

One site explained they did not distribute the eggs because they did not believe the families could afford FP. Overall, staff perceived the eggs as a two way street; prompting the nurses to be aware of potential fertility concerns for females, and prompting families to inquire about fertility and FP.

### ***Distribution***

HCP did not recommend any other modes of distribution other than placing in new patient packets and/or using as a standalone prompt during a family meeting. There were barriers to distribution, however. The main barrier was forgetting to include the eggs in new patient packets, particularly if they were pre-assembled such as Children’s Oncology Group binders. This indicates a systems barrier as the new diagnosis counseling routine would have had to be modified to contribute to the project and potentially standard of care practices.

Other barriers reported were role confusion (uncertainty regarding who would distribute the eggs; social worker vs. nurse vs. physician), uncertainty about the significance of infertility to the patient or lack of knowledge about fertility issues in general for females, concerns that HCP would not be able to answer questions about the eggs from families, and inability to identify where to refer patients and families for more information.

Two sites indicated they had FP referral resources for families. It was unknown at the time of the interviews if any family had a consultation with a reproductive health professional; however nurses reported that two families said they would be interested in a future consultation. Two sites have continued to distribute the stress eggs in new patient packets however data collection is no longer occurring.

## **Discussion and Conclusion**

### ***Discussion***

The need for FP discussions among pediatric oncology families has been established; however there is still a need to understand how to best incorporate these discussions into standard practices. It was hypothesized that providing a patient and family prompt regarding fertility would integrate into each hospital’s best method for doing so. With technologies and research rapidly advancing, HCPs are continually encumbered with new information. The stress egg prompt was designed to relieve some burden from the HCP and place the onus onto the family to inquire about FP and how it may align with their unique values on family building.



American Academy of Pediatric guidelines specifically task oncologists to discuss fertility if the treatment may affect the patient's fertility (Fallat, & Hutter, 2008, e1464). While this is a guideline, there are no formal mechanisms for carrying out the responsibilities set forth. Hence, the stress egg was designed to assist HCPs in making that connection.

Priming studies have a long-standing history within the field of health psychology and health education, though most studies have involved adults (Gerend & Sias, 2009; Harris, Bargh, & Brownell, 2009; Pierce & Lydon, 1998; Skelton & Strohmets, 1990). One study explored decision-making during stressful life events among female college students after introducing various response prompts. Pierce and Lydon (1998) found that priming had more effect on decision-making than did psychological confounders such as self-esteem and relationship patterns of the subjects (Pierce & Lydon, 1998). While not ignoring chronic patterns of behavior and cognitions, priming prompts have shown to remain effective during stressful life events such that of a cancer diagnosis.

Additionally, Legal et al. explains that the environment in which the prompt is delivered may also be an influence on response. By delivering the prompt in a "trustworthy" environment, i.e. in new patient packets with other materials families are intended to trust as valid, or hand-delivered by a trusted hospital caretaker, the subjects will likely be more influenced by the prompt (Legal, Chappe, Coiffard, & Villard-Forest, 2012). However, questions may be stifled by the lack of an institution's awareness or support for a cause.

If the institution and HCPs within the institution do not create an environment conducive to discussions about FP, however, a prompt is unlikely to succeed on its own. A variety of institutional elements are required for a discussion aid or prompt to produce reliable results, including HCP awareness and support (Graham & Logan, 2004). A similar study conducted in 2013 at an adult oncology center exhibited results that paralleled the results presented here. At the adult center, a total of 34 prompts were distributed to male patients throughout five clinics over a six-month period. Prior to providing clinics with these prompts, the research team held brief oncofertility education sessions along with brochures. Twenty-four prompts were distributed in one clinic, with one clinic reporting none distributed. There were two primary barriers to distribution which include staff forgetfulness and uncertainty about the patient's values on fertility, creating apprehension about distributing the (Koss, Rhoton-Vlasak, & Knapp, 2012).

A systematic referral process has been shown to increase discussions regarding FP for oncology patients. This is likely due to a combination of availability of resources, as well as indicating the institution has unambiguous support for the process. This support from the institution can provide patients with confidence that the sensitive topic is permissible to discuss in an open forum (Quinn et al., 2011). It is equally important to cancer education to report on and examine the causes for health promotion efforts that are not successful.

This study is not without limitations. The small sample size and homogenous demographics of participants reduces generalizability, as it is unknown if the stress eggs would have had similar impacts on other institutions. Despite limitations, it is clear that proper infrastructure is required to improve practice behavior of discussing fertility related issues and to improve family participation as issues of fertility will evolve throughout the cancer care regimen and require consistent support.

## **Conclusions: Lessons Learned**

Throughout the data collection and analyses phases, significant lessons were learned that not only may inform future oncofertility feasibility studies, but also underscores the current climate of oncofertility perception within pediatric oncology. The stress eggs cannot serve as a substitute for an institution's policy. Hospitals must have an existing level of communication

and infrastructure for priming tools to be effective. The majority of healthcare providers show reluctance to distribute the stress eggs without having staff educated in FP, adequate time to discuss options, and resources to refer to. This study highlights large scale educational needs that can be attended to by available resources.

Systemic practice change is facilitated through systemic policy change. Fertility issues are a concern for adolescent pediatric patient and this information is best disseminated via the unique relationship among patients and their healthcare providers. Healthcare providers should be armed with the best, most current information in order to provide comprehensive care for their patients. To attend to the needs for systemic change including educational needs of HCP, Moffitt Cancer Center will offer training over a period of 5 years to 250 oncology nurses on reproductive health issues among oncology patients (Vadaparampil, Hutchins, & Quinn, 2011). Through this training and adoption of a systematic referral process, oncology nurses can educate and empower their patients, both adult and pediatric, about reproductive health decisions prior to initiating treatment. Training nurses to support policy change and implement necessary infrastructure will enhance discussion prompts like the stress egg, which was lacking in this feasibility study. It is hoped that by arming individuals and families with the knowledge of their own rights while as a patient, quality of life will improve while as a survivor.

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